FAR FROM THE TREE

Parents, Children, and the Search for Identity

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SCRIBNER
New York London Toronto Sydney New Delhi

2012

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There is no such thing as reproduction. When two people decide to have a baby, they engage in an act of production, and the widespread use of the word *reproduction* for this activity, with its implication that two people are but braiding themselves together, is at best a euphemism to comfort prospective parents before they get in over their heads. In the subconscious fantasies that make conception look so alluring, it is often ourselves that we would like to see live forever, not someone with a personality of his own. Having anticipated the onward march of our selfish genes, many of us are unprepared for children who present unfamiliar needs. Parenthood abruptly catapults us into a permanent relationship with a stranger, and the more alien the stranger, the stronger the whiff of negativity. We depend on the guarantee in our children's faces that we will not die. Children whose defining quality annihilates that fantasy of immortality are a particular insult; we must love them for themselves, and not for the best of ourselves in them, and that is a great deal harder to do. Loving our own children is an exercise for the imagination.

Yet blood, in modern as in ancient societies, is thicker than water. Little is more gratifying than successful and devoted children, and few situations are worse than filial failure or rejection. Our children are not us: they carry throwback genes and recessive traits and are subject right from the start to environmental stimuli beyond our control. And yet we are our children; the reality of being a parent never leaves those who have braved the metamorphosis. The psychoanalyst D. W. Winnicott once said, "There is no such thing as a baby—meaning that if you set out to describe a baby, you will find you are describing a *baby and someone*. A baby cannot exist alone but is essentially part of a relationship." Insofar as our children resemble us, they are our most precious admirers, and insofar as they differ, they can be our most vehement detractors. From the beginning, we tempt them into imitation of us and long for what may be life's most profound compliment: their choosing to live according to our own system of values. Though many of us take pride in how different we are from our parents, we are endlessly sad at how different our children are from us.

Because of the transmission of identity from one generation to the next, most children share at least some traits with their parents. These are *vertical* identities. Attributes and values are passed down from parent to child across the generations not only through strands of DNA, but also through shared cultural norms. Ethnicity, for example, is a vertical identity. Children of color are in general born to parents of color; the genetic fact of skin pigmentation is transmitted across generations along with a self-image as a person of color, even though that self-image may be subject to generational flux. Language is usually vertical, since most people who speak Greek raise their children to speak Greek, too, even if they inflect it differently or speak another language much of the time. Religion is moderately vertical: Catholic parents will tend to bring up Catholic children, though the children may turn irreligious or convert to another faith. Nationality is vertical, except for immigrants. Blondness and myopia are often transmitted from parent to child, but in most cases do not form a significant basis for identity—blondness because it is fairly insignificant, and myopia because it is easily corrected.

Often, however, someone has an inherent or acquired trait that is foreign to his or her parents and must therefore acquire identity from a peer group. This is a *horizontal* identity. Such horizontal identities may reflect recessive genes, random mutations, prenatal influences, or values and preferences that a child does not share with his progenitors. Being gay is a horizontal identity; most gay kids are born to straight parents, and while their sexuality is not determined by their peers, they learn gay identity by observing and participating in a subculture outside the family. Physical disability tends to be horizontal, as does genius. Psychopathy, too, is often horizontal; most criminals are not raised by mobsters and must invent their own treachery. So are conditions such as autism and intellectual disability. A child conceived in rape is born into emotional challenges that his own mother cannot know, even though they spring from her trauma.

In 1993, I was assigned to investigate Deaf culture for the *New York Times*. My assumption about deafness was that it was a deficit and nothing more. Over the months that followed, I found myself drawn into the Deaf world. Most deaf children are born to hearing parents, and

those parents frequently prioritize functioning in the hearing world, expending enormous energy on oral speech and lipreading. Doing so, they can neglect other areas of their children's education. While some deaf people are good at lipreading and produce comprehensible speech, many do not have that skill, and years go by as they sit endlessly with audiologists and speech pathologists instead of learning history and mathematics and philosophy. Many stumble upon Deaf identity in adolescence, and it comes as a great liberation. They move into a world that validates Sign as a language and discover themselves. Some hearing parents accept this powerful new development; others struggle against it.

The whole situation felt arrestingly familiar to me because I am gay. Gay people usually grow up under the purview of straight parents who feel that their children would be better off straight and sometimes torment them by pressing them to conform. Those gay people often discover gay identity in adolescence or afterward, finding great relief there. When I started writing about the deaf, the cochlear implant, which can provide some facsimile of hearing, was a recent innovation. It had been hailed by its progenitors as a miraculous cure for a terrible defect and was deplored by the Deaf community as a genocidal attack on a vibrant community. Both sides have since moderated their rhetoric, but the issue is complicated by the fact that cochlear implants are most effective when they are surgically implanted early—in infants, ideally—so the decision is often made by parents before the child can possibly have or express an informed opinion. Watching the debate, I knew that my own parents would gamely have consented to a parallel early procedure to ensure that I would be straight, had one existed. I do not doubt that the advent of such a thing even now could wipe out most of gay culture. I am saddened by the idea of such a threat, and yet as my understanding of Deaf culture deepened, I realized that the attitudes I had found benighted in my parents resembled my own likely response to producing a deaf child. My first impulse would have been to do whatever I could to fix the abnormality.

Then a friend had a daughter who was a dwarf. She wondered whether she should bring up her daughter to consider herself just like everyone else, only shorter; whether she should make sure her daughter had dwarf role models; or whether she should investigate surgical limb-lengthening. As she narrated her bafflement, I saw a familiar pattern. I had been startled to note my common ground with the Deaf, and now I was identifying with a dwarf; I wondered who else was out there waiting to join our gladsome throng. I thought that if gayness, an identity, could grow out of homosexuality, an illness, and Deafness, an identity, could grow out of deafness, an illness, and if dwarfism as an identity could emerge from an apparent disability, then there must be many other categories in this awkward interstitial territory. It was a radicalizing insight. Having always imagined myself in a fairly slim minority, I suddenly saw that I was in a vast company. Difference unites us. While each of these experiences can isolate those who are affected, together they compose an aggregate of millions whose struggles connect them profoundly. The exceptional is ubiquitous; to be entirely typical is the rare and lonely state.

As my parents had misapprehended who I was, so other parents must be constantly misapprehending their own children. Many parents experience their child's horizontal identity as an affront. A child's marked difference from the rest of the family demands knowledge, competence, and actions that a typical mother and father are unqualified to supply, at least initially. The child is expressly different from most of his or her peers as well, and therefore broadly less understood or accepted. Abusive fathers visit less abuse on children who resemble them physically; if you are born to a bully, pray that you bear his features. Whereas families tend to reinforce vertical identities from earliest childhood, many will oppose horizontal ones. Vertical identities are usually respected as identities; horizontal ones are often treated as flaws.

One could argue that black people face many disadvantages in the United States today, but there is little research into how gene expression could be altered to make the next generation of children born to black parents come out with straight, flaxen hair and creamy complexions. In modern America, it is sometimes hard to be Asian or Jewish or female, yet no one suggests that Asians, Jews, or women would be foolish not to become white Christian men if they could. Many vertical identities make people uncomfortable, and yet we do not attempt to homogenize them. The disadvantages of being gay are arguably no greater than those of such vertical identities, but most parents have long sought to turn their gay children straight. Anomalous bodies are usually more frightening to people who witness them than to people who have them, yet parents rush to normalize physical exceptionalism, often at great psychic cost to themselves and their children. Labeling a child's mind as diseased—whether with autism, intellectual disabilities, or transgenderism—may reflect the discomfort that mind gives parents more than any discomfort it causes their child. Much gets corrected that might better have been left alone.

Defective is an adjective that has long been deemed too freighted for liberal discourse, but the medical terms that have supplanted it—*illness, syndrome, condition*—can be almost equally pejorative in their discreet

way. We often use *illness* to disparage a way of being, and *identity* to validate that same way of being. This is a false dichotomy. In physics, the Copenhagen interpretation defines energy/matter as behaving sometimes like a wave and sometimes like a particle, which suggests that it is both, and posits that it is our human limitation to be unable to see both at the same time. The Nobel Prize–winning physicist Paul Dirac identified how light appears to be a particle if we ask a particlelike question, and a wave if we ask a wavelike question. A similar duality obtains in this matter of self. Many conditions are both illness and identity, but we can see one only when we obscure the other. Identity politics refutes the idea of illness, while medicine shortchanges identity. Both are diminished by this narrowness.

Physicists gain certain insights from understanding energy as a wave, and other insights from understanding it as a particle, and use quantum mechanics to reconcile the information they have gleaned. Similarly, we have to examine *illness* and *identity*, understand that observation will usually happen in one domain or the other, and come up with a syncretic mechanics. We need a vocabulary in which the two concepts are not opposites, but compatible aspects of a condition. The problem is to change how we assess the value of individuals and of lives, to reach for a more ecumenical take on *healthy*. Ludwig Wittgenstein said, "All I know is what I have words for." The absence of words is the absence of intimacy; these experiences are starved for language.

The children I describe here have horizontal conditions that are alien to their parents. They are deaf or dwarfs; they have Down syndrome, autism, schizophrenia, or multiple severe disabilities; they are prodigies; they are people conceived in rape or who commit crimes; they are transgender. The timeworn adage says that the apple doesn't fall far from the tree, meaning that a child resembles his or her parents; these children are apples that have fallen elsewhere—some a couple of orchards away, some on the other side of the world. Yet myriad families learn to tolerate, accept, and finally celebrate children who are not what they originally had in mind. This transformative process is often eased and sometimes confounded by identity politics and medical progress—both of which have infiltrated households to a degree that would have been inconceivable even twenty years ago.

All offspring are startling to their parents; these most dramatic situations are merely variations on a common theme. Much as we learn the properties of a medication by studying its effect at extremely high doses, or look at the viability of a construction material by exposing it to unearthly supertemperatures, so we can understand the universal phenomenon of difference within families by looking at these extreme cases. Having exceptional children exaggerates parental tendencies; those who would be bad parents become awful parents, but those who would be good parents often become extraordinary. I take the anti-Tolstoyan view that the unhappy families who reject their variant children have much in common, while the happy ones who strive to accept them are happy in a multitude of ways.

Because prospective parents have ever-increasing options to choose against having children with horizontal challenges, the experiences of those who have such children are critical to our larger understanding of difference. Parents' early responses to and interactions with a child determine how that child comes to view himself. These parents are also profoundly changed by their experiences. If you have a child with a disability, you are forever the parent of a disabled child; it is one of the primary facts about you, fundamental to the way other people perceive and decipher you. Such parents tend to view aberrance as illness until habituation and love enable them to cope with their odd new reality—often by introducing the language of identity. Intimacy with difference fosters its accommodation.

Broadcasting these parents' learned happiness is vital to sustaining identities that are now vulnerable to eradication. Their stories point a way for all of us to expand our definitions of the human family. It's important to know how autistic people feel about autism, or dwarfs about dwarfism. Self-acceptance is part of the ideal, but without familial and societal acceptance, it cannot ameliorate the relentless injustices to which many horizontal identity groups are subject and will not bring about adequate reform. We live in xenophobic times, when legislation with majority support abrogates the rights of women, LGBT people, illegal immigrants, and the poor. Despite this crisis in empathy, compassion thrives at home, and most of the parents I have profiled love across the divide. Understanding how they came to think well of their own children may give the rest of us motive and insight to do the same. To look deep into your child's eyes and see in him both yourself and something utterly strange, and then to develop a zealous attachment to every aspect of him, is to achieve parenthood's self-regarding, yet unselfish, abandon. It is astonishing how often such mutuality has been realized—how frequently parents who had supposed that they couldn't care for an exceptional child discover that they can. The parental predisposition to love prevails in the most harrowing of circumstances. There is more imagination in the world than one might think.

I had dyslexia as a child; indeed, I have it now. I still cannot write by hand without focusing on each letter as I form it, and even when I do

so, some letters are out of order or omitted. My mother, who identified the dyslexia early, began to work on reading with me when I was two. I spent long afternoons in her lap, learning to sound out words, training like an Olympic athlete in phonetics; we practiced letters as though no shapes could ever be lovelier than theirs. To keep my attention, she gave me a notebook with a yellow felt cover on which Winnie-the-Pooh and Tigger were sewn; we made flash cards and played games with them in the car. I reveled in the attention, and my mother taught with a sense of fun, as though it was the best puzzle in the world, a private game between us. When I was six, my parents applied for my admission to eleven schools in New York City, and all eleven turned me down on grounds that I would never learn to read and write. A year later, I was enrolled in a school where the principal grudgingly allowed my advanced reading skills to overrule test scores that predicted I would never learn to read at all. The standards of perpetual triumph were high in our house, and that early victory over dyslexia was formative: with patience, love, intelligence, and will, we had trounced a neurological abnormality. Unfortunately, it set the stage for our later struggles by making it hard to believe that we couldn't reverse the creeping evidence of another perceived abnormality—my being gay.

People ask when I knew I was gay, and I wonder what that knowledge entails. It took some time for me to become aware of my sexual desires. The realization that what I wanted was exotic, and out of step with the majority, came so early that I cannot remember a time preceding it. Recent studies have shown that as early as age two, male children who will grow up to be gay are averse to certain types of rough-and-tumble play; by age six, most will behave in obviously gender-nonconforming ways. Because I could tell early on that many of my impulses were unmasculine, I embarked on further acts of self-invention. When, in first grade, each of us was asked to name his favorite food and everyone else said ice cream or hamburgers or French toast, I proudly chose *ekmek kadayiff* with *kaymak*, which I used to order at an Armenian restaurant on East Twenty-Seventh Street. I never traded a baseball card, but I did recount the plots of operas on the school bus. None of this made me popular.

I was popular at home, but I was subject to corrections. My mother, my brother, and I were at Indian Walk Shoes when I was seven, and as we were leaving, the salesman asked what color balloons we'd like. My brother wanted a red balloon. I wanted a pink one. My mother countered that I didn't want a pink balloon and reminded me that my favorite color was blue. I said I really wanted the pink, but under her glare, I took the blue one. That my favorite color is blue but I am still gay is evidence of both my mother's influence and its limits. She once said, "When you were little, you didn't like to do what other kids liked to do, and I encouraged you to be yourself." She added, only half-ironically, "I sometimes think I let things go too far." I have sometimes thought she didn't let them go far enough. But her encouragement of my individuality, although doubtless ambivalent, has shaped my life.

My new school had quasi-liberal ideas and was supposed to be integrated—which meant that our class included a few black and Latino kids on scholarship who mostly socialized with one another. My first year there, Debbie Camacho had a birthday party in Harlem, and her parents, unacquainted with the logic of New York private education, scheduled it for the same weekend as homecoming. My mother asked how I would feel if no one attended my birthday party, and insisted that I attend. I doubt many kids in my class would have gone to the party even if there hadn't been such a convenient excuse, but in fact, only two white kids went out of a class of forty. I was frankly terrified of being there. The birthday girl's cousins tried to get me to dance; everyone spoke Spanish; there were unfamiliar fried foods; and I had something of a panic attack and went home in tears.

I drew no parallels between everyone's avoidance of Debbie's party and my own unpopularity, even when, a few months later, Bobby Finkel had a birthday party and invited everyone in the class but me. My mother called his mother on the assumption that there had been a mistake; Mrs. Finkel said that her son didn't like me and didn't want me at his party. My mother picked me up at school on the day of the party and took me to the zoo, and for a hot fudge sundae at Old-Fashioned Mr. Jennings. It's only in retrospect that I imagine how hurt my mother was on my behalf—more hurt than I was, or let myself notice I was. I didn't guess then that her tenderness was a bid to compensate for the insults of the world. When I contemplate my parents' discomfort with my gayness, I can see how vulnerable my vulnerabilities made her, and how much she wanted to preempt my sadness with the assurance that we were our own good time. Forbidding the pink balloon must be held as partly a protective gesture.

I'm glad my mother made me go to Debbie Camacho's birthday party—because I think it was the right thing to do and because, though I couldn't see it at the time, it was the beginning of an attitude of tolerance that allowed me to stomach myself and find happiness in adulthood. It's tempting to paint myself and my family as beacons of liberal exceptionalism, but we weren't. I teased one African-American student in my elementary school by claiming he resembled a picture in our social studies book of a tribal child in an African *rondavel*. I didn't think that this was racist; I thought it was funny, and vaguely true. When I was older, I remembered my behavior with deep regret, and when the person in question found me on Facebook, I apologized profusely. I said that my only excuse was that it was not easy to be gay at the school, and that I'd acted out the prejudice I experienced in the form of prejudice toward others. He accepted my apology, and mentioned that he was also gay; I was humbled that he had survived, where so much of both kinds of bias were in play.

I floundered in the tricky waters of elementary school, but at home, where bias was never tinged with cruelty, my more intractable deficits were minimized and my quirks were mostly humored. When I was ten, I became fascinated by the tiny principality of Liechtenstein. A year later, my father took us along on a business trip to Zürich, and one morning my mother announced that she'd arranged for us all to drive to Liechtenstein's capital, Vaduz. I remember the thrill that the whole family was going along with what was clearly my wish and mine alone. In retrospect, the Liechtenstein preoccupation seems peculiar, but the same mother who forbade the pink balloon thought up and arranged that day: lunch in a charming café, a tour of the art museum, a visit to the printing office where they make the country's distinctive postage stamps. Although I did not always feel approved of, I always felt acknowledged and was given the latitude of my eccentricity. But there were limits, and pink balloons fell on the wrong side of them. Our family rule was to be interested in otherness from within a pact of sameness. I wanted to stop merely observing the wide world and inhabit its wideness: I wanted to dive for pearls, memorize Shakespeare, break the sound barrier, learn to knit. From one angle, the desire to transform myself can be seen as an attempt to unshackle myself from an undesirable way of being. From another, it was a gesture toward my essential self, a crucial pivot toward whom I was to become.

Even in kindergarten, I spent recess making conversation with my teachers because other children didn't get it; the teachers probably didn't get it, either, but they were old enough to be polite. By seventh grade, I ate lunch most days in the office of Mrs. Brier, secretary of the head of the lower school. I graduated from high school without visiting the cafeteria, where I would have sat with the girls and been laughed at for doing so, or with the boys and been laughed at for being the kind of boy who should really sit with the girls. The impulse to conformity that so often defines childhood never existed for me, and when I began to think about sexuality, the nonconformity of same-sex desires thrilled me—the realization that what I wanted was even more different and forbidden than all sex is to the young. Homosexuality felt to me like an

Armenian dessert or a day in Liechtenstein. I nonetheless thought that if anyone found out I was gay, I would have to die.

My mother didn't want me to be gay because she thought it wouldn't be the happiest course for me, but equally, she didn't like the image of herself as the mother of a gay son. The problem wasn't that she wanted to control *my* life—although she did, like most parents, genuinely believe that her way of being happy was the best way of being happy. The problem was that she wanted to control *her* life, and it was her life as the mother of a homosexual that she wished to alter. Unfortunately, there was no way for her to fix her problem without involving me.

I learned to hate this aspect of my identity profoundly and early because that crouching posture echoed a family response to a vertical identity. My mother thought it was undesirable to be Jewish. She had learned this view from my grandfather, who kept his religion secret so he could hold a high-level job in a company that did not employ Jews. He belonged to a suburban country club where Jews were not welcome. In her early twenties, my mother was briefly engaged to a Texan, but he broke it off when his family threatened to disinherit him if he married a Jew. For her, it was a trauma of self-recognition, because until then she had not thought of herself as a designated Jew; she had thought she could be whomever she appeared to be. Five years later, she chose to marry my Jewish father and live in a largely Jewish world, but she carried the anti-Semitism within her. She would see people who fit certain stereotypes and say, "Those are the people who give us a bad name." When I asked her what she thought of the much sought-after beauty of my ninth-grade class, she said, "She looks very Jewish." Her method of rueful self-doubt was organized for me around being gay: I inherited her gift for discomfort.

Long after childhood, I clung to childish things as a dam against sexuality. This willful immaturity was overlaid with an affected Victorian prudery, aimed not at masking but at obliterating desire. I had some farfetched idea that I would be Christopher Robin forever in the Hundred Acre Wood; indeed, the final chapter of the *Winnie-the-Pooh* books felt so much like my story that I couldn't bear to hear it, though I had my father read me all the other chapters hundreds of times. *The House at Pooh Corner* ends, "Wherever they go, and whatever happens to them on the way, in that enchanted place on top of the Forest, a little boy and his Bear will always be playing." I decided that I would be that boy and that bear, that I would freeze myself in puerility, because what growing up portended for me was too humiliating. At thirteen, I bought a copy of *Playboy* and spent hours studying it, trying to resolve

my discomfort with female anatomy; it was much more grueling than my homework. By the time I reached high school, I knew I had to have sex with women sooner or later and felt that I couldn't do so, and thought often about dying. The half of me that wasn't planning to be Christopher Robin playing forever in an enchanted place was planning to be Anna Karenina throwing myself in front of a train. It was a ludicrous duality.

When I was in eighth grade at the Horace Mann School in New York, an older kid nicknamed me Percy as a shorthand for my demeanor. We were on the same school-bus route, and each day when I boarded, he and his cohort would chant, "Percy! Percy! Percy!" I sometimes sat with a Chinese-American student who was too shy to talk to anyone else (and turned out to be gay himself), and sometimes with a nearly blind girl who was also the object of considerable cruelty. Sometimes, everyone on the bus chanted that provocation the entire ride. "Per-cy! Per-cy! Per-cy! Per-cy!" at the top of their lungs for forty-five minutes: all the way up Third Avenue, along the FDR Drive, across the Willis Avenue Bridge, the length of the Major Deegan Expressway, and onto 246th Street in Riverdale. The blind girl kept repeating that I should "just ignore it," and so I sat there pretending unconvincingly that it wasn't happening.

Four months after it began, I came home one day and my mother asked, "Has something been happening on the school bus? Have other students been calling you Percy?" A classmate had told his mother, who in turn had called mine. When I admitted it, she hugged me for a long time, then asked why I hadn't told her. It had never occurred to me: partly because talking about something so degrading seemed only to reify it, partly because I thought there was nothing to be done, and partly because I felt that the qualities for which I was being tortured would be abhorrent to my mother, too, and I wanted to protect her from disappointment.

Thereafter, a chaperone rode on the school bus and the chanting stopped. I was merely called "faggot" on the bus and at school, often within hearing distance of teachers who raised no objections. That same year, my science teacher told us that homosexuals developed fecal incontinence because their anal sphincters were destroyed. Homophobia was ubiquitous in the 1970s, but the smug culture of my school delivered a sharply honed version of it.

In June of 2012, the *New York Times Magazine* published an article by Horace Mann alumnus Amos Kamil about some male faculty members' predatory abuse of boys at the school while I was a student there. The article quoted students who developed addiction issues and other self-destructive behavior in the wake of such episodes; one man had committed suicide in middle age as the culmination of despair that his family traced to the youthful exploitation. The article made me profoundly sad—and confused, because some teachers accused of such acts had been kinder to me than anyone else at my school during a desolate time. My beloved history teacher took me out to dinner, gave me a copy of the Jerusalem Bible, and talked with me during free periods when other students wanted nothing to do with me. The music teacher awarded me concert solos, let me call him by his first name and hang out in his office, and led the glee club trips that were among my happiest adventures. They seemed to recognize who I was and thought well of me anyway. Their implicit acknowledgment of my sexuality helped me not to become an addict or a suicide.

When I was in ninth grade the school's art teacher (who was also a football coach) kept trying to strike up a conversation with me about masturbation. I was paralyzed: I thought it might be a form of entrapment, and that if I responded, he'd tell everyone that I was gay, and I'd be even more of a laughingstock than I already was. No other faculty member ever made a move on me—perhaps because I was a skinny, socially awkward kid with glasses and braces, perhaps because my parents had a reputation for protective vigilance, perhaps because I assumed a self-insulating arrogance that made me less vulnerable than some others.

The art teacher was removed when allegations against him emerged soon after my conversations with him. The history teacher was let go and committed suicide a year later. The music teacher, who was married, survived the ensuing "reign of terror," as one gay faculty member later called it, when many gay teachers were ousted. Kamil wrote to me that the firings of nonpredatory gay teachers grew out of "a misguided attempt to root out pedophilia by falsely equating it with homosexuality." Students spoke monstrously of and even to gay teachers because their prejudice was so obviously endorsed by the school community.

The head of the theater department, Anne MacKay, was a lesbian who quietly survived the recriminations. Twenty years after I graduated, she and I began corresponding by e-mail. I drove to the east end of Long Island to visit her a decade later when I learned she was dying. We had both been contacted by Amos Kamil, who was then researching his article, and had both been unsettled by the allegations he shared. Miss MacKay had been the wise teacher who once explained gently that I was teased because of how I walked, and tried to show me a more confident stride. She staged *The Importance of Being Earnest* my

senior year so that I could have a star turn as Algernon. I had come to thank her. But she had invited me to apologize.

At a previous job, she explained, word had got around that she lived with another woman, parents had complained, and she'd gone into a kind of hiding for the rest of her career. Now she regretted the formal distance she'd sustained and felt she had failed the gay students to whom she might have been a beacon—although I knew, and she did, too, that if she'd been more open, she'd have lost her job. When I was her student, I never thought to wonder about greater intimacy than we had, but talking decades later, I realized how forlorn we'd both been. I wish we could have been the same age for a while, because who I am at forty-eight would be a good friend for who she was when she was teaching young me. Off campus, Miss MacKay was a gay activist; now, I am, too. When I was in high school, I knew she was gay; she knew I was gay; yet each of us was imprisoned by our homosexuality in a way that made direct conversation impossible, leaving us with only kindness to give each other instead of truth. Seeing her after so many years stirred up my old loneliness, and I was reminded of how isolating an exceptional identity can be unless we resolve it into horizontal solidarity.

In the unsettling online reunion of Horace Mann alumni that followed the publication of Amos Kamil's story, one man wrote of his sadness for both the abuse victims and the perpetrators, saying of the latter, "They were wounded, confused people trying to figure out how to function in a world that taught them that their homosexual desire was sick. Schools mirror the world we live in. They can't be perfect places. Not every teacher will be an emotionally balanced person. We can condemn these teachers. But this deals with a symptom only, not the original problem, which is that an intolerant society creates self-hating people who act out inappropriately." Sexual contact between teachers and students is unacceptable because it exploits a power differential that clouds the demarcation between coercion and consent. It often causes irrecoverable trauma. It clearly did so for the students Kamil interviewed and described. Wondering how my teachers could have done this, I thought that someone whose core being is deemed a sickness and an illegality may struggle to parse the distinction between that and a much greater crime. Treating an identity as an illness invites real illness to make a braver stand.

Sexual opportunity comes often to young people, especially in New York. One of my chores was to walk our dog before bedtime, and when I was fourteen, I discovered two gay bars near our apartment: Uncle Charlie's Uptown and Camp David. I would walk Martha, our Kerry

Blue terrier, on a circuit that included these two emporiums of denimed flesh, watching the guys spill out into Lexington Avenue while Martha tugged gently on the leash. One man who said his name was Dwight followed me and pulled me into a doorway. I couldn't go home with Dwight or the others because if I did, I'd be turned into someone else. I don't remember what Dwight looked like, but his name makes me wistful. When I eventually had sex with a man, at seventeen, I felt that I was severing myself forever from the normal world. I went home and boiled my clothes, then took a scalding, hourlong shower, as though my transgression could be sterilized away.

When I was nineteen, I read an ad in the back of *New York* magazine that offered surrogate therapy for people who had issues with sex. I still believed that the problem of whom I wanted was subsidiary to the problem of whom I didn't want. I knew the back of a magazine was not a good place to find treatment, but my condition was too embarrassing to reveal to anyone who knew me. Taking my savings to a walk-up office in Hell's Kitchen, I subjected myself to long conversations about my sexual anxieties, unable to admit to myself or the so-called therapist that I was actually just not interested in women. I didn't mention the busy sexual life I had by this time with men. I began "counseling" with people I was encouraged to call "doctors," who would prescribe "exercises" with my "surrogates"—women who were not exactly prostitutes but who were also not exactly anything else. In one protocol, I had to crawl around naked on all fours pretending to be a dog while the surrogate pretended to be a cat; the metaphor of enacting intimacy between mutually averse species is more loaded than I noticed at the time. I became curiously fond of these women, one of whom, an attractive blonde from the Deep South, eventually told me that she was a necrophiliac and had taken this job after she got into trouble down at the morgue. You were supposed to keep switching girls so your ease was not limited to one sexual partner; I remember the first time a Puerto Rican woman climbed on top of me and began to bounce up and down, crying ecstatically, "You're in me! You're in me!" and how I lay there wondering with anxious boredom whether I had finally achieved the prize and become a qualified heterosexual.

Cures seldom work swiftly and completely for anything other than bacterial infections, but it can be hard to see that when social and medical realities are in rapid flux. My own recovery has been from the perception of illness. That office on Forty-Fifth Street shows up in my dreams: the necrophiliac who found my pale, sweaty form close enough to a corpse to float her boat; the mission-driven Latino woman who introduced me to her body with so much jubilation. My treatment took

only two hours a week for about six months, and it gave me an ease with women's bodies that was vital to subsequent heterosexual experiences I'm glad to have had. I truly loved some of the women with whom I later had relationships, but when I was with them, I could never forget that my "cure" was a distilled manifestation of self-loathing, and I have never entirely forgiven the circumstances that disposed me to make the obscene effort. Stretching my psyche between Dwight and those cat-women made romantic love almost impossible for me during my early adulthood.

My interest in profound differences between parents and children arose from a need to investigate the locus of my regret. While I'd like to blame my parents, I have come to believe that a lot of my pain came from the larger world around me, and some of it came from me. In the heat of an argument, my mother once told me, "Someday you can go to a therapist and tell him all about how your terrible mother ruined your life. But it will be *your* ruined life you're talking about. So make a life for yourself in which you can feel happy, and in which you can love and be loved, because that's what's actually important." You can love someone but not accept him; you can accept someone but not love him. I wrongly felt the flaws in my parents' acceptance as deficits in their love. Now, I think their primary experience was of having a child who spoke a language they'd never thought of studying.

How is any parent to know whether to erase or celebrate a given characteristic? When I was born in 1963, homosexual activity was a crime; during my childhood, it was a symptom of illness. When I was two, *Time* magazine wrote, "Even in purely nonreligious terms, homosexuality represents a misuse of the sexual faculty. It is a pathetic little second-rate substitute for reality, a pitiable flight from life. As such it deserves fairness, compassion, understanding and, when possible, treatment. But it deserves no encouragement, no glamorization, no rationalization, no fake status as minority martyrdom, no sophistry about simple differences in taste—and, above all, no pretense that it is anything but a pernicious sickness."

When I was growing up, we nonetheless had close family friends who were gay—neighbors, and surrogate great-uncles to my brother and me, who spent holidays with us because their own families would not have them. I was always bewildered that Elmer had gone off to World War II halfway through medical school, fought on the Western Front, and then opened a gift shop when he came home. For years, I heard that the terrible things he saw in the war had changed him, and that he didn't have the stomach for medicine after his return. It was only after Elmer died that Willy, his partner of fifty years, explained to me that no one would have considered going to an openly gay doctor in 1945. The horrors of war had propelled Elmer into integrity, and he paid its price by spending his adulthood painting amusing bar stools and selling crockery. Elmer and Willy were a great romance in many ways, but an undertone of sadness for what might have been informed their lives. The gift shop was an apology for medicine; Christmas with us was an apology for family. I am humbled by Elmer's choice; I do not know that I would have had the courage to choose likewise, nor the discipline to keep regret from undermining my love had I done so. Though Elmer and Willy would never have seen themselves as activists, their galvanizing sorrow and that of others like them was the precondition of my happiness and that of others like me. When I understood their story more richly, I recognized that my parents' fears for me were not simply the product of overactive imaginations.

In my adulthood, being gay is an identity; the tragic narrative my parents feared for me is no longer inevitable. The happy life I now lead was unimaginable when I was asking for pink balloons and *ekmek kadayiff*—even when I was being Algernon. Yet, the trifecta view of homosexuality as a crime, an illness, and a sin remains potent. I sometimes felt that it was easier for me to ask people about their disabled children, their children conceived in rape, their children who committed crimes, than it would have been to look squarely at how many parents still respond to having children like me. Ten years ago, a *New Yorker* poll asked parents whether they would prefer to see their child gay, happily partnered, fulfilled, and with children, or straight, single or unhappily partnered, and childless. One out of three chose the latter. You cannot hate a horizontal identity much more explicitly than to wish unhappiness and likeness for your children over happiness and difference. In the United States, new antigay laws emerge with monotonous regularity; in December 2011, Michigan enacted the Public Employee Domestic Partner Benefit Restriction Act, which bars gay employees' partners from health-care coverage, despite allowing city and county employers to provide health-care coverage to all other family members, including uncles, nieces, and cousins. Meanwhile, in much of the larger world, the identity I inhabit remains unimaginable. In 2011, Uganda came close to passing a bill that would have made some homosexual acts punishable by death. An article in *New York* magazine about gay people in Iraq includes this information: "The bodies of gay men, often mutilated, began turning up on the street. Hundreds of men are believed to have been killed. Gay men's rectums had been glued shut, and they had been force-fed laxatives and water until their insides exploded."

Much of the debate around sexual-orientation laws has turned on the idea that if you choose homosexuality, it should not be protected, but if you are born with it, perhaps it should. Members of minority religions are protected not because they are born that way and can't do anything about it, but because we affirm their right to discover, declare, and inhabit the faith with which they identify. Activists got homosexuality removed from the official list of mental illnesses in 1973, yet gay rights remain contingent on claims that the condition is involuntary and fixed. This cripple-like model of sexuality is depressing, but as soon as anyone posits that homosexuality is chosen or mutable, lawmakers and religious leaders try to cure and disenfranchise the gay people in their purview. Today, men and women continue to be "treated" for homosexuality at religious reform camps and in the offices of unscrupulous or misguided psychiatrists. The ex-gay movement in evangelical Christianity deranges gay people by the tens of thousands by seeking to persuade them, contrary to their experience, that desire is wholly volitional. The founder of the antihomosexual organization MassResistance has argued that gays should be made specific targets of discrimination, due to the supposedly voluntary nature of their ostensible perversion.

Those who think that a biological explanation of gayness will improve the sociopolitical position of gay people are also sadly mistaken, as the response to recent scientific findings makes clear. The sexologist Ray Blanchard has described a "fraternal birth order effect," which holds that the chance of producing gay sons goes up steadily with each male fetus a mother carries. Within weeks of publishing this data, he was called by a man who had decided against hiring a surrogate who had borne previous boys, saying to Blanchard, "That's not really what I want . . . especially if I'm paying for it." The arthritis drug dexamethasone is used off-label to treat women at risk for producing daughters with a condition that partially masculinizes their genitalia. Maria New, a researcher at Mount Sinai Hospital in New York, has suggested that dexamethasone given in early pregnancy will also reduce the chances that such babies will grow up to be lesbian; indeed, she has described the treatment as making girls more interested in childbearing and homemaking, less aggressive, and more shy. It has been posited that such therapy might curb lesbianism even in the general population. In animal studies, prenatal exposure to dexamethasone seems to cause many health problems, but if any medication can actually limit lesbianism, researchers will come up with a safer one. Medical findings such as these will continue to have serious social implications. If we develop prenatal markers for homosexuality, many couples will abort their gay children; if we come up with a viable preventative drug, many parents will be willing to try it.

I would no more insist that parents who don't want gay children must have them than I would that people who don't want children at all must have them. Nonetheless, I cannot think about Blanchard's and New's research without feeling like the last quagga. I am not evangelical. I don't need to verticalize my identity onto my children, but I would hate for my horizontal identity to vanish. I would hate it for those who share my identity, and for those who lie outside it. I hate the loss of diversity in the world, even though I sometimes get a little worn out by being that diversity. I don't wish for anyone in particular to be gay, but the idea of no one's being gay makes me miss myself already.

All people are both the objects and the perpetrators of prejudice. Our understanding of the prejudice directed against us informs our responses to others. Universalizing from the cruelties we have known, however, has its limits, and the parents of a child with a horizontal identity often fail at empathy. My mother's issues with Judaism didn't make her much better at dealing with my being gay; my being gay wouldn't have made me a good parent to a deaf child until I'd discerned the parallels between the Deaf experience and the gay one. A lesbian couple I interviewed who had a transgender child told me they approved of the murder of George Tiller, the abortion provider, because the Bible said that abortion was wrong, and yet they were astonished and frustrated at the intolerance they had encountered for their identity and their child's. We are overextended in the travails of our own situation, and making common cause with other groups is an exhausting prospect. Many gay people will react negatively to comparisons with the disabled, just as many African-Americans reject gay activists' use of the language of civil rights. But comparing people with disabilities to people who are gay implies no negativity about gayness or disability. Everyone is flawed and strange; most people are valiant, too. The reasonable corollary to the queer experience is that everyone has a defect, that everyone has an identity, and that they are often one and the same.

It's terrifying to me to think that without my mother's sustained intervention, I might never have learned fluency in letters; I am grateful every day for the sufficient resolution of my dyslexia. Conversely, while I might have had an easier life if I had been straight, I am now wedded to the idea that without my struggles, I would not be myself, and that I like being myself better than I like the idea of being someone else—someone I have neither the ability to imagine nor the option

of being. Nevertheless, I have often wondered whether I could have ceased to hate my sexual orientation without Gay Pride's Technicolor fiesta, of which this writing is one manifestation. I used to think that I would be mature when I could simply be gay without emphasis. I have decided against this viewpoint, in part because there is almost nothing about which I feel neutral, but more because I perceive those years of self-loathing as a yawning void, and celebration needs to fill and overflow it. Even if I adequately address my private debt of melancholy, there is an outer world of homophobia and prejudice to repair. Someday, I hope this identity may devolve into a simple fact, free of both party hats and blame, but that's some ways off. A friend who thought Gay Pride was getting a bit carried away with itself once suggested we organize Gay Humility Week. It's a good idea, but its time has not yet come. Neutrality, which appears to lie halfway between shame and rejoicing, is in fact the endgame, reached only when activism becomes unnecessary.

It is a surprise to me to like myself; among all the elaborate possibilities I contemplated for my future, that never figured. My hard-won contentment reflects the simple truth that inner peace often hinges on outer peace. In the gnostic gospel of St. Thomas, Jesus says, "If you bring forth what is within you, what is within you will save you. If you do not bring forth what is within you, what is within you will destroy you." When I run up against the antigay positions of modern religious bodies, I often wish that St. Thomas's words were canonical because his message embraces many of us with horizontal identities. Keeping the homosexuality locked away within me nearly destroyed me, and bringing it forth has nearly saved me.

Although men who murder usually target people not related to them, nearly 40 percent of women who inflict death kill their own babies. Reports of human children discarded in Dumpsters and the overburdened foster-care network point to the ability of human beings to detach. Oddly, this seems to have at least as much to do with the infant's appearance as with its health or character. Parents will usually take home a child with a life-threatening internal defect, but not one with a minor visible defect; at a later stage, some parents will reject even children with severe burn scars. Manifest disabilities affront parents' pride and their need for privacy; everyone can see that this child isn't what you wanted, and you must either accept the world's pity or insist on your own pride. At least half of the children available for adoption in the United States have disabilities of some kind. Half of those available for adoption, however, still constitutes only a small proportion of disabled children.

Modern love comes with more and more options. For most of history, people married only members of the opposite sex, from their own class, race, denomination, and geographical location—all increasingly disputed boundaries. Similarly, people were supposed to accept the children given to them because one could do little to choose or change them. Birth control and fertility technologies have severed the bond between sex and procreation: intercourse does not necessarily engender babies, nor is it requisite to produce them. The analysis of embryos prior to implantation and the expanding domain of prenatal testing give parents access to a wealth of information to help them decide whether to initiate, continue, or terminate a pregnancy. The choices are broadening every day. People who believe in the right to opt for healthy, normative children refer to *selective abortion*; people to whom that idea is anathema refer to *commercial eugenics*, evoking a world stripped of variety and vulnerability. A vast industry of pediatric medicine implies that responsible parents should revamp their children in various ways, and parents expect doctors to correct their children's perceived defects: to administer human growth hormone to make the short ones taller, to fix a cleft lip, to normalize ambiguous genitalia. These optimizing interventions are not exactly cosmetic, but they are not necessary for survival. They have led social theorists such as Francis Fukuyama to speak of a "post-human future" in which we will eliminate the variety within mankind.

Yet while medicine promises to normalize us, our social reality remains a miscellany. If the cliché is that modernity makes people more similar, as tribal headdresses and frock coats alike give way to T-shirts and jeans, the reality is that modernity comforts us with trivial uniformities even as it allows us to become more far-flung in our desires and our ways of realizing them. Social mobility and the Internet allow anyone to find others who share his quiddities. No closed circle of French aristocrats or farm boys from Iowa has been tighter than these new clusters of the electronic age. As the line between illness and identity is challenged, the strength of these online supports is a vital setting for the emergence of true selves. Modern life is lonely in many ways, but the ability of everyone with access to a computer to find like-minded people has meant that no one need be excluded from social kinship. If the physical or psychic place to which you were born wants no more of you, an infinitude of locales of the spirit beckons. Vertical families are famously breaking down in divorce, but horizontal ones are proliferating. If you can figure out who you are, you can find other people who are the same. Social progress is making disabling conditions easier to live with just as medical progress is eliminating them. There is something tragic about this confluence, like those operas in which the hero realizes he loves the heroine just as she expires.

Parents willing to be interviewed are a self-selecting group; those who are bitter are less likely to tell their stories than those who have found value in their experience and want to help others in similar circumstances to do the same. No one loves without reservation, however, and everyone would be better off if we could destigmatize parental ambivalence. Freud posits that any declaration of love masks some degree of odium, any hatred at least a trace of adoration. All that children can properly require of their parents is that they tolerate their own muddled spectrum—that they neither insist on the lie of perfect happiness nor lapse into the slipshod brutality of giving up. One mother who lost a child with a serious disability worried in a letter to me that if she felt relieved, her grief was not real. There is no contradiction between loving someone and feeling burdened by that person; indeed, love tends to magnify the burden. These parents need space for their ambivalence, whether they can allow it for themselves or not. For those who love, there should be no shame in being exhausted—even in imagining another life.

Some marginalizing conditions, such as schizophrenia and Down syndrome, are thought to be entirely genetic; others, such as being transgender, are believed to be largely environmental. Nature and nurture get positioned as opposing influences, when it is more often, in the science writer Matt Ridley's phrase, "nature via nurture." We know that environmental factors can alter the brain, and conversely, that brain chemistry and structure partly determine how much we can be affected by external influences. Much as a word exists as a sound, a set of marks on a page, and a metaphor, nature and nurture are diverse conceptual frameworks for a single set of phenomena.

Nevertheless, it is easier for parents to tolerate the syndromes assigned to nature than those thought to result from nurture, because guilt is reduced for the former category. If your child has achondroplastic dwarfism, no one will accuse you of bad behavior for having produced such a child. However, an individual's success at accommodating his own dwarfism and valuing his own life may be largely a function of nurture. If you have a child conceived in rape, you may encounter some blame—either for the rape itself, or for your decision not to abort the pregnancy. If you have a child who has committed serious crimes, it is often assumed that you did something wrong as a parent, and people whose children do not commit crimes may condescend accordingly. But there is increasing evidence that some criminality may be hardwired, and that even the most admirable moral instruction may be ineffective in swaying a child who is so predisposed to gruesome acts that, in Clarence Darrow's phrase, his murderous crime "was inherent in his organism, and came from some ancestor." You can enable or discourage criminal tendencies, but the result in either direction is by no means guaranteed.

The social perception of whether any supposed deficit is the parents' fault is always a critical factor in the experience of both children and parents. The Nobel Prize–winning geneticist James D. Watson, who has a son with schizophrenia, once told me that Bruno Bettelheim, the midcentury psychologist who asserted that autism and schizophrenia were caused by poor parenting, was "after Hitler, the most evil person of the twentieth century." The attribution of responsibility to parents is often a function of ignorance, but it also reflects our anxious belief that we control our own destinies. Unfortunately, it does not save anyone's children; it only destroys some people's parents, who either crumble under the strain of undue censure or rush to blame themselves before anyone else has time to accuse them. The parents of a woman who had died of a genetic illness told me they felt terrible because they hadn't had prenatal genetic testing, which did not exist at the time their daughter was born. Many parents similarly organize their guilt around some fictitious misstep. I had lunch one afternoon with a highly educated activist whose son suffers from severe autism. "It's because I went skiing while I was pregnant," she said to me. "The altitude isn't good for the developing child." I felt so sad hearing this. The roots of autism are confusing, and there are questions as to what may dispose children toward the condition, but altitude is not on the list. This intelligent woman had so assimilated a narrative of self-blame that she didn't know that it had come out of her imagination.

There is something ironic in prejudice against the disabled and their families, because their plight might befall anybody. Straight men are unlikely to wake up gay one morning, and white children don't become black; but any of us could be disabled in an instant. People with disabilities make up the largest minority in America; they constitute 15 percent of the population, though only 15 percent of those were born with their disability and about a third are over sixty-five. Worldwide, some 550 million people are disabled. The disability-rights scholar Tobin Siebers has written, "The cycle of life runs in actuality from disability to temporary ability back to disability, and that only if you are among the most fortunate."

In typical circumstances, to have children who won't care for you in your dotage is to be King Lear. Disability changes the reciprocity equation; severely disabled adults may still require attention in midlife, when other grown children are attending to their own parents. The most effortful stages of dealing with a child with special needs are generally held to be his first decade, when the situation is still novel and confusing; the second decade, because cognizant disabled adolescents, like most teenagers, feel the need to defy their parents; and the decade when the parents become too impaired to continue to provide care and worry acutely about what will happen to their child after they are gone. This account fails, however, to reflect that the first decade does not vary so much from the norm as the subsequent ones do. Taking care of a helpless disabled infant is similar to caring for a helpless nondisabled infant, but continuing to tend to a dependent adult requires a special valor.

In an oft-cited 1962 article, the rehabilitation counselor Simon Olshansky bluntly wrote, "Most parents who have a mentally defective child suffer chronic sorrow throughout their lives regardless of whether the child is kept at home or 'put away.' The parents of a mentally defective child have little to look forward to; they will always be burdened by the child's unrelenting demands and unabated dependency. The woes, the trials, the moments of despair will continue until either their own deaths or the child's death. Release from this chronic sorrow may be obtainable only through death." One mother of a twenty-year-old with severe disabilities said to me, "It's as if I'd had a baby every year for the past twenty years—and who would choose to do that?"

The difficulties such families face have long been acknowledged by the outside world; only recently have the pleasures become a topic of general conversation. *Resilience* is the contemporary gloss on what used to be thought of as perseverance. It is both a way to reach larger objectives—functionality and happiness—and an objective in itself, inseparable from what Aaron Antonovsky, progenitor of the study of resilience, calls a "sense of coherence." Parents whose expectations are diverted by children with horizontal identities need resilience to rewrite their future without bitterness. Those children need resilience, too, and ideally parents foster it. Ann S. Masten wrote in *American Psychologist* in 2001, "The great surprise of resilience research is the ordinariness of the phenomenon." Resilience used to be posited as an extraordinary trait, seen in the Helen Kellers of the world, but cheery recent research suggests that most of us have the potential for it, and that cultivating it is a crucial part of development for everyone.

Even so, more than a third of parents of children with special needs report that caring for them has negative effects on their physical and mental health. Researchers designing a study of the effects of sustained stress on aging settled on bringing up a child with special needs as a universally acknowledged stressor. Comparing women who had had that experience with women who had not, they found the caretakers had shorter telomeres—the protection at the end of a chromosome—than the control group, which meant that they were aging more rapidly at the cellular level. Taking care of disabled children causes your biological age to outpace your chronological age, which is associated with premature rheumatic conditions, heart failure, reduced immune function, and earlier death through cell senescence. One study reported that fathers who described a significant caregiving burden died younger than fathers with a lighter caregiving burden.

This is true, and so is its opposite. One study found that 94 percent of parents with disabled kids said they "were getting along as well as most other families" without such children. Another said that most parents they surveyed believe "that this has brought them closer to their spouse, other family members, and friends; taught them what's important in life; increased their empathy for others; engendered personal growth; and made them cherish their child even more than if he or she had been born healthy." Yet another found that 88 percent of parents of children with disabilities felt happy when they thought about their child. Four out of five agreed that the disabled child had made their family closer; and a full 100 percent endorsed the statement "I have increased compassion for others due to my experience."

Buoyancy may bring about the results it would appear to reflect; the children of mothers initially rated as optimists had more advanced skills at two than did the children in similar condition of pessimistic mothers. The Spanish philosopher Miguel de Unamuno wrote, "It is not usually our ideas that make us optimists or pessimists, but it is our optimism or pessimism that makes our ideas." Disability is not predictive of the happiness of either the parent or the child, which reflects the larger puzzle that people who have won the lottery are, in the long run and on average, only marginally happier than amputees—people in each category having adjusted rather quickly to their new normal.

The popular life coach Martha Beck wrote a passionate book about the "lovely epiphanies" she experienced in tending to her son with Down syndrome. The writer Clara Claiborne Park said in the 1970s of her autistic daughter, "I write now what 15 years past I would still not have thought possible to write: that if today I were given the choice to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands—because

out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love." One of the mothers I interviewed said she had had no sense of purpose until her son was born with severe disabilities. "Suddenly, I had this object for all my energy," she explained. "He gave me a whole new reason to be alive." Such responses are not uncommon. One woman wrote, "This thought runs like a bright golden thread through the dark tapestry of our sorrow. We learn so much from our children—in patience, in humility, in gratitude for other blessings we had accepted before as a matter of course; so much in tolerance; so much in faith—believing and trusting where we cannot see; so much in compassion for our fellow man; and yes, even so much in wisdom about the eternal values in life." When I worked in a juvenile prison, a long-serving correctional officer there exhorted her bevy of felons, "You gotta take your mess and find yourself a message!"

While optimism can propel day-to-day life forward, realism allows parents to regain a feeling of control over what is happening and to come to see their trauma as smaller than it first seemed. The potential pitfalls are wishful thinking, self-blame, escapism, substance abuse, and avoidance; resources might include faith, humor, a strong marriage, and a supportive community, along with financial means, physical health, and higher education. There is no definitive roster of strategies, although words such as *transformation* and *enlightenment* occur. Studies are highly contradictory and seem often to reflect researcher bias. Numerous studies, for example, show that divorce is more frequent among parents of children with disabilities, and an equal number show the divorce rate is significantly lower among such parents; further research finds divorce rates consistent with those in the general population. Parents who cope poorly with a disabled child are worn down by the effort in the same way that parents who are coping successfully seem to grow strong, but all of them are both worn down and strengthened. Being part of a group seems consistently to have meaning; the redemptive power of intimacies born from struggle is immense. In our Internet age, when every challenge or disability has a community attached to it, the parents of people with any given challenge can find their horizontal community as well. Although most families do find meaning in their predicament, fewer than one in ten professionals who deal with them believes it. "I was determined *not* to be around folks who saw us as tragic," one exasperated mother wrote. "Unfortunately, that included my family, most professionals, and just about everyone else I knew." A doctor's or social worker's refusal to recognize such parents' reality because it is happier than anticipated is a kind of betrayal.

Perhaps the most difficult prospect facing parents of challenged children is institutionalization: a practice that is now more euphemistically—if cumbersomely—called *out-of-home placement*. Institutionalization used to be the norm, and parents who wanted to keep their disabled children at home had to fight a system designed to take them away. That all began to change in 1972, after the exposure of the horrific conditions at Willowbrook, a home for the mentally retarded in Staten Island, New York. Unethical medical research had been conducted on residents, and the place was grotesquely overcrowded, with deplorable sanitary facilities and physically abusive staff. "Untended, some smeared with their own feces, many of the children were unclothed and all were simply left to sit in the ward all day," according to the *New York Times*. "The only sound picked up by the technicians was something of an eerie communal wail." Patients at such facilities experienced "institutionalism," a condition marked by withdrawal, loss of interest, submissiveness, lack of initiative, impaired judgment, and reluctance to leave the hospital setting, which one researcher likened to "mental bedsores."

After Willowbrook, placing children became suspect. Now, parents whose children are impossible to cope with have a tough time finding an appropriate placement and must confront a system that can make them feel irresponsible for pursuing this option. The pendulum needs to swing to an appropriate middle. The question is never easy; as with abortion, people should be able to make the choice that is right for them without having to feel worse about it than they already do. Disabled children are now supposed to live in the "least restrictive environment," a laudable objective that should ideally apply to other family members as well. As one researcher has pointed out, "Placing many severely handicapped children and youth in the least restrictive environment of their families results in their family being required to live in a highly restrictive manner." The child, the parents, and the siblings are all deeply affected by placement decisions.

My study is of families who accept their children, and how that relates to those children's self-acceptance—a universal struggle we negotiate partly through the minds of others. In turn, it looks at how the acceptance of the larger society affects both these children and their families. A tolerant society softens parents and facilitates self-esteem, but that tolerance has evolved because individuals with good self-esteem have exposed the flawed nature of prejudice. Our parents are metaphors for ourselves: we struggle for their acceptance as a displaced way of struggling to accept ourselves. The culture is likewise a metaphor for our parents: our quest for high esteem in the larger world is only a sophisticated manifestation of our primal wish for parental love. The triangulation can be dizzying.

Social movements have debuted in sequence: first religious freedom, women's suffrage, and race rights, and then gay liberation and disability rights. That last category has become a catchall for difference of many kinds. The women's movement and the civil rights movement were focused on vertical identities, so they gained traction first; the horizontal identities could not emerge until the pattern had been set by those with greater strength. Each of these movements borrows unabashedly from the ones before, and now some borrow from those that followed them.

Preindustrial societies were cruel to those who were different, but did not segregate them; their care was the responsibility of their families. Postindustrial societies created benevolent institutions for the disabled, who were often whisked away at the first sign of anomaly. That dehumanizing tendency set the stage for eugenics. Hitler murdered more than 270,000 people with disabilities on the grounds that they were "travesties of human form and spirit." The presumption that disability could be extirpated was current worldwide. Laws to permit involuntary sterilization and abortion were passed in Finland, Denmark, Switzerland, and Japan, as well as in twenty-five American states. By 1958, over sixty thousand Americans had been forcibly neutered. Chicago passed an ordinance in 1911 that decreed, "No person who is diseased, maimed, mutilated, or in any way deformed so as to be an unsightly or disgusting object in or on the public ways or other public places in this city, shall therein or thereon expose himself to public view." It stayed on the books through 1973.

The disability rights movement seeks, at the most basic level, to find accommodation of difference rather than erasure of it. One of its signal successes is to understand that the interests of children, parents, and society do not necessarily coincide, and that the children are the least able to stand up for themselves. Many people with profound differences maintain that even well-run asylums, hospitals, and residences are analogous to the treatment of African-Americans under Jim Crow. Medical diagnosis is implicated in this separate-and-unequal response. Sharon Snyder and David Mitchell, both academics in disability studies, contend that those who seek cures and treatments often "subjugate the very populations they intend to rescue." Even today, American children with disabilities are four times more likely than nondisabled ones to have less than a ninth-grade education. Some 45 percent of Britons with disabilities and some 30 percent of working-age Americans with disabilities live below the poverty line. As recently as 2006, the Royal College of Obstetricians and Gynaecologists in London proposed that doctors consider killing infants with extreme disabilities.

In spite of these persisting challenges, the disability rights movement has made tremendous strides. The US Rehabilitation Act of 1973, passed by Congress over President Nixon's veto, prohibited discrimination against people with disabilities in any federally funded program. This was followed by the Americans with Disabilities Act, passed in 1990, and several subsequent acts that appeared to shore it up. In 2009, Vice President Joe Biden opened the Special Olympics by declaring special-needs advocacy a "civil rights movement" and announcing the new post of special assistant to the president for disability policy. The courts, however, have narrowed the scope of laws pertinent to disability, and local governments have often ignored them altogether.

Members of minorities who wish to preserve their self-definition need to define themselves in opposition to the majority. The more accepting the majority is of them, the more rigorously they need to do so, because their separate identity collapses if they countenance its integration into the majority world. Multiculturalism rejects the 1950s vision of a world in which everyone is subsumed by uniform Americanness, and chooses one in which we all inhabit our own treasured particularities. In his classic work *Stigma*, Erving Goffman argues that identity is formed when people assert pride in the thing that made them marginal, enabling them to achieve personal authenticity and political credibility. The social historian Susan Burch calls this "the irony of acculturation": society's attempts to assimilate a group often cause that group to become more pronounced in its singularity.

When I was in college in the mid-1980s, it was common practice to speak of the "differently abled" rather than the "disabled." We joked about the "differently gruntled" and the "differently agreeable." These days, if you talk about an autistic child, he differs from "typical" children, while a dwarf differs from "average" people. You are never to use the word *normal*, and you are certainly never to use the word *abnormal*. In the vast literature about disability rights, scholars stress the separation between *impairment*, the organic consequence of a condition, and *disability*, the result of social context. Being unable to move your legs, for example, is an impairment, but being unable to enter the public library is a disability.

An extreme version of the social model of disability is summarized by the British academic Michael Oliver: "Disability has nothing to do with the body, it is a consequence of social oppression." This is untrue, even specious, but it contains a valid challenge to revise the prevalent opposite assumption that disability resides entirely in the mind or body of the disabled person. Ability is a tyranny of the majority. If most people could flap their arms and fly, the inability to do so would be a disability. If most people were geniuses, those of moderate intelligence would be disastrously disadvantaged. There is no ontological truth enshrined in what we think of as good health; it is merely a convention, one that has been strikingly inflated in the past century. In 1912, an American who lived until the age of fifty-five had had a good, long life; now, death at fifty-five is considered a tragedy. Because most people can walk, being unable to walk is a disability; so is being unable to hear; and so is being unable to decipher social cues. It's a matter of votes, and the disabled question these majority decisions.

Medical advances allow parents to avoid producing certain kinds of disabled children; many disabilities may be ameliorated. It is not easy to determine when to exploit these options. Ruth Hubbard, an emerita professor of biology at Harvard, maintains that expectant parents who test for Huntington's because they have a family history of the disease are in a quandary: "If they decide on abortion, they are as much as saying that a life lived in the knowledge that one will eventually die of Huntington's disease is not worth living. What does that say about their own life and the lives of their family members who now know that they have the gene for Huntington's disease?" The philosopher Philip Kitcher has referred to genetic screening as "laissez-faire eugenics." Marsha Saxton, a lecturer at Berkeley who has spina bifida, writes, "Those of us with screenable conditions represent living adult fetuses that didn't get aborted. Our resistance to the systematic abortion of 'our young' is a challenge to the 'nonhumanness,' the nonstatus of the fetus." Snyder and Mitchell speak of how the elimination of disability marks "the completion of modernity as a cultural project."

Some in the disability rights camp urge acceptance of whatever child you conceive, as though it were immoral not to conform to reproductive destiny. This is what the bioethicist William Ruddick calls the "'hospitality' view of women," which finds anyone who terminates a pregnancy nonmaternal, ungenerous, and unwelcoming. In fact, prospective parents are dealing in the abstract with something that could become tangible, and that's never an informed way to make a choice: the idea of a child or a disability is extremely different from the reality.

There is a problematic collision between feminism's prioritizing of legal abortion and the disability rights movement's opposition to any social system that devalues difference. "The fears are genuine, rational, and terrifying," the disability activist Laura Hershey wrote. "We all face the prospect that what is supposed to be a private decision—the termination of a pregnancy—might become the first step in a campaign to eliminate people with disabilities." She may be naïve about the motive, but correct about the result. Most Chinese people don't hate girls, and no one in China is pursuing a campaign to eliminate women. But couples have been legally limited to one child since 1978, and because many prefer a boy, they give the girls up for adoption or abandon them. Although prospective parents may not be out to eliminate people with disabilities, medical advances giving them the ability to make radical decisions could undoubtedly reduce the disabled population considerably. "In this liberal and individualistic society, there may be no need for eugenic legislation," Hubbard wrote. "Physicians and scientists need merely provide the techniques that make individual women, and parents, responsible for implementing the society's prejudices by choice."

Some activists have argued against the entire Human Genome Project, maintaining that it implies the existence of a perfect genome. The Genome Project has been construed this way partly because its authors pitched it to funders as a way to cure maladies, without acknowledging that there is no universal standard of well-being. Disability advocates argue that in nature, variation is the only invariable. Donna Haraway, who teaches feminist and cultural studies, has described the project as an "act of canonization" that could be used to establish ever-narrower standards. Michel Foucault, writing before the mapping of the genome was feasible, described how "a technology of abnormal individuals appears precisely when a regular network of knowledge and power has been established." In other words, the spectrum of normality gets constrained when those in power consolidate their privilege. In Foucault's view, the idea of normality "claimed to ensure the physical vigor and the moral cleanliness of the social body; it promised to eliminate defective individuals, degenerate and bastardized populations. In the name of biological and historical urgency, it justified the racisms of the state." It thus encouraged people outside normality to perceive themselves as helpless and inadequate. If, as Foucault had also argued, "life is what is capable of error" and error itself is "at the root of what makes human thought and its history," then to prohibit error would be to end evolution. Error lifted us out of the primordial slime.

Deborah Kent is a congenitally blind woman who has written about the pain that society's prejudice against blindness has caused her. Describing a level of self-acceptance that was almost unheard of before the disability rights movement came into its own, Kent has said that her blindness is, to her, a neutral trait like her brown hair. "I didn't long for sight any more than I yearned for a pair of wings," she wrote

in an essay in 2000. "Blindness presented occasional complications, but it seldom kept me from anything I wanted to do." Then she and her husband, Dick, decided to have a baby, and she was shocked that he wanted their child to be seeing. "I believed that my life could not have turned out any better if I had been fully sighted. If my child were blind, I would try to ensure it every chance to become a self-fulfilled, contributing member of society. Dick said he agreed with me completely. But he was more troubled than he wished me to know. If he could accept blindness in me, why would it be devastating to him, even for a moment, if our child were blind as well?" Deborah entered into conception with grave concern. "I did not know if I could bear his devastation if our baby turned out to be blind like me."

After their daughter was born, Deborah's mother also expressed fear that the baby might be blind. "I was stunned," Deborah wrote. "My parents raised all three of their children, including my blind brother and me, with sensitivity and unwavering love. In all of us they tried to nurture confidence, ambition, and self-respect. Yet blindness had never become neutral for them, any more than it had for Dick." The baby turned out to be seeing, as Dick discovered by getting her to track his movements. He called his in-laws to tell them the news; he has since reminisced about the day his daughter turned to watch his moving fingers. "In his voice, I hear an echo of the excitement and relief that were so vivid for him on that long-ago morning," Deborah wrote. "Each time I hear the story I feel a twinge of the old pain, and for a few moments I am very much alone again."

Her aloneness reflects a disjunction between her own perception—that being blind is an identity—and her husband's—that it is an illness. I am both sympathetic to her point of view and perturbed by it. I imagine how I would feel if my brother were to announce a fervent wish that my nephews be straight and call everyone to revel if it turned out to be true. It would hurt me. Being blind and being gay are different, but having a selfhood that others perceive as undesirable is identical. But our decisions to maximize health (however complicated a category that word may reference) and avoid illness (ditto) do not necessarily devalue those who are sick or otherwise different. My own battles with depression have contributed to a meaningful identity for me, but if I were choosing between a depression-prone child and one who would never suffer such ravages, I'd go with option B in a heartbeat. Even though the illness would probably become a locus of intimacy for us, I still wouldn't want it to happen.

Most adults with horizontal identities do not want to be pitied or admired; they simply want to get on with their lives without being stared at. Many dislike Jerry Lewis's use of pathetic children to get funds for genetic research. The NBC news correspondent John Hockenberry, who has a spinal injury, said, "'Jerry's kids' are people in wheelchairs on television raising money to find a way to prevent their ever having been born." The anger is pervasive. "Adults responded to my difference by helping me, but some of my schoolmates responded by calling me names," wrote Rod Michalko, who is blind. "Only much later did I realize that helping and name-calling amounted to the same thing." Arlene Mayerson, an expert in disability rights law, contends that benevolence and good intentions have been among disabled people's worst enemies throughout history. The able-bodied can be generous narcissists: they eagerly bestow what they feel good about giving without considering how it will be received.

Conversely, the social model of disability demands that society modify the way business is done to empower people with disabilities, and we make such adjustments only when lawmakers accept that life can be painful for those who live at the margins. Patronizing gestures can be justly scorned, but increased empathy is often a precondition of political acceptance and an engine of reform. Many disabled people say that the social disapprobation they experience is much more burdensome than the disability from which they suffer, maintaining simultaneously that they suffer only because society treats them badly, and that they have unique experiences that set them apart from the world—that they are eminently special and in no way different.

A study that sought to determine whether money correlated with happiness revealed that poverty is connected to despair, but that once one gets out of poverty, wealth has little effect on happiness. What does correlate is how much money a person has compared to his social group. There is much scope to thrive on downward comparisons. Wealth and ability are both relative concepts. There are broad spectra in all these areas, and wide, shadowy borderlands in mental and physical disability as there are in socioeconomic status. A broad range of people can feel rich—or able—in relation to the context they live in. When a condition is not stigmatized, the comparisons are less oppressive.

Nonetheless, at the far end of the disability spectrum is a zone that corresponds to poverty, a place of severe privation, where rhetoric cannot make things better. The disability poverty line varies from one community to another, but it does exist. To deny the medical realities such people negotiate is equivalent to denying the financial realities of the slum child. The body and the mind can be agonizingly broken. Many disabled people experience debilitating pain, struggle with intellectual incapacities, and live in permanent proximity to death.

Repairing the body and repairing entrenched social prejudice are objectives that dance a troubling waltz; either fix can have unwelcome consequences. A repaired body may have been achieved through brutal trauma and in response to unfair social pressures; a repaired prejudice can eliminate the rights that its existence had called into being. The question of what constitutes any protected difference carries enormous political weight. Disabled people are protected by fragile laws, and if they are judged to have an identity rather than an illness, they may forfeit those safeguards.

All kinds of attributes make one less able. Illiteracy and poverty are disabilities, and so are stupidity, obesity, and boringness. Extreme age and extreme youth are both disabilities. Faith is a disability insofar as it constrains you from self-interest; atheism is a disability inasmuch as it shields you from hope. One might see power as a disability, too, for the isolation in which it imprisons those who wield it. The disability scholar Steven R. Smith posited, "A completely painless existence could also quite plausibly be seen as deficient for most people." Likewise, any of these characteristics can embody strength, some more easily than others. We are all differently abled from one another, and context—which is socially constructed—often decides what will be protected and indulged. Being gay was a disability in the nineteenth century in a way that it isn't now; and it is now a disability in some locations in a way that it isn't in others; and it was a disability for me when I was young and it isn't one for me today. The whole matter is intensely unstable. No one has ever suggested legal protections for ugly people to make up for the misaligned features that will compromise their personal and professional lives. For people disabled by inherent moral perplexity, we offer not support but imprisonment.

Because there is not yet a coherent understanding of horizontal identities as a collective category, those who strive for horizontal rights often rely on the disability movement's methodical rejection of illness models. Insofar as these conceptualizations of rights are about identity, they draw on the model of Alcoholics Anonymous and other 12-step recovery groups. AA was the first to suggest managing a disease by claiming it as an identity and drawing on the support of peers with a similar condition—that according meaning to a problem was crucial to resolving it. In a way, this near-paradox can be reduced to the last clause of Reinhold Niebuhr's Serenity Prayer, which is a tenet of the recovery movement: "Father, give us courage to change what must be altered, serenity to accept what cannot be helped, and the insight to know the one from the other."

Although we have moved in recent decades away from illness models and toward identity models, such a shift is not always ethically defensible. After I had come to see deafness and dwarfism and autism and transgenderism as identities worthy of appreciation, I came up against the pro-ana and pro-mia movements, which seek to remove the negative associations around anorexia and bulimia, promoting them as lifestyle choices rather than illnesses. Pro-ana and pro-mia websites offer "thinspiration" tips on crash diets, review use of emetics and laxatives, and validate competitive weight-loss postings. People who follow the advice on such sites may die: Anorexia has the highest mortality rate of any mental illness. To propose that anorexics are merely exploring an identity is as morally lax as accepting the belief of gang members that they are merely pursuing an identity that happens to entail killing people. It's clear that identity is a finite concept. What's not clear is the location of its boundaries. In my own life, dyslexia is an illness, while being gay is an identity. I wonder, though, whether it would have been the other way around if my parents had failed to help me compensate for the dyslexia, but had achieved the goal of altering my sexuality.

The wish to fix people reflects pessimism about their condition and optimism about the method of repair. In *Autobiography of a Face*, Lucy Grealy describes the childhood cancer of the jaw that left her permanently disfigured—and, to her mind, grotesque. I knew Lucy, though not well, and I didn't find her ugly. I always wondered where the deep conviction of her own repulsiveness came from because it informed everything she did, no matter how her charm distracted from her missing jaw. She wrote about how she prepared for one of her innumerable unsuccessful reconstructive surgeries and thought, "Maybe this wasn't my actual face at all but the face of some interloper, some ugly intruder, and my 'real' face, the one I was meant to have all along, was within reach. I began to imagine my 'original' face, the one free from all deviation, all error. I believed that if none of this had happened to me, I would have been beautiful." Lucy's death of a drug overdose at thirty-nine testifies in part to the oppressive costs by which anomalous people make their way through endless processes of repair.

If the surgeries had worked, Lucy might have had a happy life, just as good as if she'd come to ease with her appearance. That her face turned out to be irremediable makes one wonder whether her mind would have been similarly beyond mending. What might have happened if her energy had been focused on the singular intelligence that produced such a chronicle of intractable despair? I, too, would have tried the things Lucy did—possibly with the same result; I have always tried to mend whatever can be fixed and tend to accept only the inevitable. Her dream of vanquishing her problem, which was for decades sustained by doctors, did her in. Recent academic work suggests that people who know their condition to be irreversible are happier than those who believe their condition may be ameliorated. In such cases, ironically, hope may be the cornerstone of misery.

In 2003, a suit was brought in England against a doctor who had performed a late-stage abortion on a woman who would have given birth to a child with a cleft palate. Such abortions are legal for women likely to produce a child with a severe genetic defect, and the question was whether this defect fit that definition. Court filings quoted another mother whose son had a congenital cleft palate attesting, "I definitely would not have had a termination even if this baby had a cleft palate or lip, these days it can be repaired to such a high standard. It is not a disability." An untreated severe cleft palate can have dire consequences and is undeniably a disability. But there is no simple equation whereby the existence of the fix means that the condition is no longer a disability; rectifying a condition is not the same thing as forestalling it. Bruce Bauer, chief of plastic surgery at Children's Memorial Hospital in Chicago, who corrects facial deformities, said the children on whom he operates deserve "the chance to look like what they truly are—no different from anyone else." But whether the surgical fix makes them "no different" or permanently disguises their difference is a loaded question with broad ramifications.

The press abounds with heartwarming stories of surgical interventions, such as that of Chris Wallace, the boy born with clubfeet who now plays pro football. "I love my feet," he has said. People who seek surgical interventions almost always speak in terms of correction. Transgender people speak of sex-reassignment procedures as a means of remedying a birth defect. Those who champion cochlear implants for deaf people use the same rhetoric. The line between cosmetic intervention—what some call "technoluxe"—and corrective procedures can be a fine one, as can the line between becoming one's best self and conforming to oppressive social norms. What about the mother who has her daughter's ears pinned because she is being teased at school, or the man who seeks a surgical antidote to his baldness? Such people may be eliminating a problem, or they may merely be caving to peers.

Insurance companies deny coverage for many corrective procedures on grounds that they are cosmetic. In fact, a cleft palate can cause disfiguration, difficulty eating, ear infections that lead to hearing loss, severe dental problems, speech and language impairments, and—perhaps as a consequence of all this—severe psychological problems. Lucy Grealy's lack of a jawbone might not have been considered a crucial loss by some people, but for her it was mortal. Conversely, even a positive surgical outcome can pose difficulty for parents. On a website for parents of children with cleft palates, Joanne Green writes, "The doctor tells you that everything went perfectly. So why, then, when you see the baby, does everything look anything but perfect? Your sweet, laughing, loving, trusting, happy baby of two hours ago is now sick and hurting. And then you will take a good look at the face. Not the suture line, not the swelling, but the face. And you will be shocked at the difference you will see in your baby's face. Very few parents are initially thrilled with the surgery. The baby will almost seem to be another baby. After all, you loved the old one!"

How urgent is any problem and how dire is the solution? That is the proportion that must be entertained. It is always both essential and impossible to tease apart the difference between the parents' wanting to spare the child suffering and the parents' wanting to spare themselves suffering. It is not pleasant to be suspended between two ways of being; when I asked a dwarf what she thought of limb-lengthening, a process undertaken in childhood that can give someone the normalized appearance of average height, she said that it would just make her "a tall dwarf." At best, medical interventions allow people to move from the margins toward a more accommodating center; at worst, they leave people feeling further compromised and no less alienated. Alice Domurat Dreger, who has written about transgenderism and about conjoined twins, averred, "Far from feeling like a rejection of the child, normalization surgery may feel to some parents like a manifestation of full love and unconditional love. But parents may also seek surgical fixes because they feel like they will know how to be a parent to that child, whereas they often feel uncertain how to be a parent to this one."

People of higher socioeconomic status tend toward perfectionism, and have a harder time living with perceived defects. One French study said baldly, "The lower classes show a higher tolerance for severely handicapped children." An American study bears out that conclusion, inasmuch as higher-income families are "more apt to stress independence and self-development," while lower-income families emphasize "interdependence among family members." Better-educated, more-affluent families are more likely to seek placement for children, and white families do so more often than minority families, though disturbingly high numbers of minority parents lose children to foster care. I did back-to-back interviews with a wealthy white woman who had a low-functioning autistic son, and an impoverished African-American woman whose autistic son had many of the same symptoms. The more privileged woman had spent years futilely trying to make her son better. The less advantaged woman never thought she could make her son better because she'd never been able to make her own life better, and she was not afflicted with feelings of failure. The first woman found it extremely difficult to deal with her son. "He breaks everything," she said unhappily. The other woman had a relatively happy life with her son. "Whatever could be broken got broken a long time ago," she said. Fixing is the illness model; acceptance is the identity model; which way any family goes reflects their assumptions and resources.

A child may interpret even well-intentioned efforts to fix him as sinister. Jim Sinclair, an intersex autistic person, wrote, "When parents say, 'I wish my child did not have autism,' what they're really saying is, 'I wish the autistic child I have did not exist, and I had a different (non-autistic) child instead.' Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces." There are both additive and subtractive models of most conditions: either the person has an invasive condition that can be removed, such as an infection, or the person has been diminished by the condition, as when an organ gives out. Layers of illness or variance may be piled on top of a persisting "normal" person, who is obscured by them—or the condition may be integral to the person. If we give a deaf person hearing, are we releasing him into fuller selfhood, or compromising his integrity? Does reforming a criminal's mind give him a more authentic self, or just one that suits the rest of us? Most parents suppose that an authentic nonautistic self is hidden inside autistic people, but Sinclair and many others with autism do not see anyone else inside them, any more than I would see a straight person—or a pro baseball player—locked away within me. It is not clear that we can set free the child planned through love within a child conceived in rape. Perhaps genius, too, can be seen as an invasive illness.

Aimee Mullins was born without fibula bones in her shins, and so her legs were amputated below the knee when she was a year old. Now she is a fashion model with prosthetic legs. "I want to be seen as beautiful because of my disability, not in spite of it," she said. "People kept asking me, 'Why do you want to get into this world that's so bitchy and so much about physical perfection?' That's why. That's why I want to do it." Bill Shannon, who was born with a degenerative hip condition, devised a break-dancing technique using crutches and a skateboard. He developed a cult following on the avant-garde dance scene for the work he described as a natural outgrowth of his efforts to retain mobility. He was courted by Cirque du Soleil, but since he didn't envision himself as a Vegas entertainer, he agreed to train someone else in his routines. He taught an able-bodied performer how to move around on crutches just as he had. Cirque du Soleil's act "Varekai," which uses Shannon's technique and choreography, has been a huge success. Shannon's disability is not a risible spectacle, but the wellspring of a provocative and original enterprise. More recently, Oscar Pistorius, the South African who has two prosthetic lower legs, was ranked among the top 400-meter racers in the world and competed in the London Olympics in 2012. *Time* magazine named him one of the hundred most influential people in the world, and he has endorsement contracts with Nike and Thierry Mugler. Some kinds of grace would not have entered the world if everyone's hips and legs worked the same way. Deformity has been brought into beauty's fold, a catalyst for justice rather than an affront to it, and society has changed enough to marvel at a dancer on crutches, a model with prosthetic legs, an athlete whose speed relies on carbon-fiber calves.

Flaunting the visible technologies that compensate for a disability, as Mullins, Shannon, and Pistorius do, can empower those who use them. For many people, however, such trumpeting of their reliance on robotics is inconceivable. I suffer from depression and spent ten years seeking effective treatment for it. As someone whose ability to function would be compromised without psychotropic medications, I know the weird discomfort of recognizing that without enhancements I'd be someone else. I've also felt ambivalence about upgrading my emotional life, and I sometimes feel that I'd be truer to myself if I were morose, withdrawn, and hiding in bed. I know why some people make the choice not to medicate. Bewildered doctors and uncomprehending parents often question disabled people who reject the latest procedures and devices. Those disabled people, however, may be angered by the prospect of interventions that would make them function more like nondisabled people without mitigating the hard reality of their disabling condition. Some may even curse the contraptions that keep them going: dialysis, medication, wheelchairs, prosthetics, voice-processing software. I began taking psychotropic medications well past the age of consent and feel some ownership of the decision. Many interventions, however, have to occur at a much earlier age. The parents and doctors who pursue surgical corrections and early intervention for infants initiate a life narrative that they deem morally and pragmatically right, but they can never fully anticipate what will come of their decisions.

The disability rights movement assumes that most people who are alive are glad to be alive, or would be if they had adequate supports—that the wish to be dead is as aberrant among the disabled as in anyone else. Nonetheless, individuals have been named as plaintiffs in successful suits against their own birth, complaints generally brought by their parents on their behalf. The principle extrapolates from *wrongful death*, which results from physician negligence, and *wrongful birth*, which can be claimed when a family has not received adequate prenatal counseling. Wrongful-birth suits are brought by parents in their own names and will compensate only for costs they incur as parents—usually for care and support until the child is eighteen. *Wrongful life* compensates the disabled person rather than his or her parents and may entail funds across a lifetime. A wrongful-life suit purports to cover not a loss but a gain: the fact of someone's existence.

In 2001, France's highest appeals court awarded a large sum to a child with Down syndrome for "the damage of being born." The court stipulated that "the child's handicap is the actual damage to be compensated, and not his loss of happiness"—meaning that he deserved financial compensation for the indignity of being alive. The same court later granted compensation to a seventeen-year-old born mentally disabled, deaf, and nearly blind, saying that if his mother's gynecologist had diagnosed rubella during pregnancy, she would have had an abortion and her son would not have experienced a lifetime of pain. Disabled French people went ballistic about the implication that being dead was better than being handicapped. One father said, "I do hope that is not the way the rest of society looks upon our children—since this would be unbearable." In response to extensive protests, the French legislature outlawed wrongful-life suits.

In the United States, the idea of wrongful life has been validated in four states, although twenty-seven others have explicitly rejected it. Nonetheless, wrongful-life suits have been brought in connection with Tay-Sachs disease, deafness, hydrocephalus, spina bifida, rubella syndrome, Down syndrome, and polycystic kidney disease, and the courts have given awards, most strikingly in *Curlender v. Bio-Science Laboratories*. A couple who underwent genetic screening were not told they were carriers for Tay-Sachs; they had a daughter with the condition who died at the age of four. They argued, "The reality of the 'wrongful-life' concept is that such a plaintiff both *exists* and *suffers*. Had defendants not been negligent, the plaintiff might not have come into existence at all." They received compensation for the cost of care, and damages for parental pain and suffering.

Although wrongful-life cases address an ontological question about what kind of life is worth living, this is hardly what prompts them. Being disabled entails colossal expense, and most parents who launch wrongful-life suits do so in an attempt to guarantee care for their children. In an ugly twist, mothers and fathers must discharge the obligations of responsible parenting by stating in legal documents that they wish their children had never been born.

Some people can bear a great deal of pain and still experience great happiness, while others are made unrelentingly miserable by less acute pain. There's no way to know how much pain any particular baby can cope with, and by the time the parents form accurate perceptions of this, social prohibitions, legal strictures, and hospital policies make it exceedingly difficult to discontinue treatment. Even among self-aware adults, many people with apparently barren existences cling to life, while others with enviable situations kill themselves.

Over ten years, I interviewed more than three hundred families for this book, some briefly and some in depth, producing nearly forty thousand pages of interview transcripts. I interviewed but did not write about irreligious parents of fundamentalist children; parents of children with dyslexia and other learning disabilities; parents of obese children and of addicted children; parents of giants with Marfan syndrome, of limbless children with phocomelia syndrome, and of adult "thalidomide babies"; parents of premature babies; parents of depressed and bipolar children, of children with AIDS or cancer. I talked to parents who had adopted disabled children or children of a different race from another country. I talked to parents of intersex children who couldn't decide in what gender to raise them. I talked to the parents of supermodels, of bullies, and of the blind.

It would have been easier to write a book about five conditions. I wanted, however, to explore the spectrum of difference, to show that raising a child of extraordinary abilities is in some ways like raising a child of reduced capacities, to show that a child's traumatic origin (rape) or traumatic acts (crime) can have surprising parallels to the condition of his mind (autistic, schizophrenic, prodigious) or of his body (dwarfism, deafness). Each of the ten categories I explored poses a unique but related set of questions, which together describe the spectrum of issues faced by parents of children with horizontal identities. I found excellent scholarship on each of my individual topics, and some on the smaller collective topics (general books on disability, on retardation, on genius), but nothing addressing this overarching issue of illness and identity.

Each of these chapters poses a particular set of questions, and taken

together, they indicate a spectrum of issues faced by parents of children with horizontal identities, and by those children themselves. The six chapters that follow this one deal with categories long classified as illnesses, while the four that follow those describe categories that appear to be more socially constructed. I have relied primarily on American and British interview subjects, but investigated one non-Western context in which what we perceive as an aberrant illness is commonplace—by studying congenital deafness in a village in northern Bali—and one non-Western context in which what we perceive as an aberrant identity is commonplace—by interviewing Rwandan women who conceived children in rape during the 1994 genocide.

Though I have gathered statistics, I have relied primarily on anecdotes because numbers imply trends, while stories acknowledge chaos. If you talk to a family, you have to process conflicting narratives, trying to reconcile the genuine beliefs—or canny manipulations—of various parties. I worked on a psychodynamic model according to which people's interactions with me in the microcosm of journalistic neutrality indicated how they interact with the world. Throughout, I refer to members of the families I interviewed by first name. I do this not to create a gloss of intimacy, as self-help books often try to do, but because various members of families share last names, and this is the least cumbersome way to keep track of my subjects.

I had to learn a great deal to be able to hear these men and women and children. On my first day at my first dwarf convention, I went over to help an adolescent girl who was sobbing. "This is what I look like," she blurted between gasps, and it seemed she was half laughing. "These people look like me." Her mother, who was standing nearby, said, "You don't know what this means to my daughter. But it also means a lot to me, to meet these other parents who will know what I'm talking about." She assumed I, too, must be a parent of a child with dwarfism; when she learned that I was not, she chuckled, "For a few days, now, you can be the freakish one." Many of the worlds I visited were animated by such a fierce sense of community that I experienced pangs of jealousy. I would not wish to trivialize the difficulty of these identities, but I knew about that going in. The revelation was all the joy.

While denying the anger and tedium of parenting can be crushing, dwelling on it is also a mistake. Many of the people I interviewed said that they would never exchange their experiences for any other life—sound thinking, given that exchange is unavailable. Cleaving to our own lives, with all their challenges and limitations and particularities, is vital. And that should not be exclusively a horizontal principle; that should be handed down from generation to generation with the silver spoons and the folktales from the old country. The British critic Nigel Andrews once wrote, "If something or someone doesn't work, it's in a state of grace, progress, and evolution. It will attract love and empathy. If it does work, it has merely completed its job and is probably dead."

Having a severely challenging child intensifies life. The lows are almost always very low; the highs are sometimes very high. It takes an act of will to grow from loss: the disruption provides the opportunity for growth, not the growth itself. Constant high levels of stress may age parents of profoundly disabled children, making them crankier and more vulnerable, yet some cultivate a deep and abiding resilience. It turns out they have grown more skilled at handling other life stresses. Even as the downside wears you thin, the upside keeps on giving. The more difficult the problem, the more profound these positives may be. One study explains, "Mothers reporting higher levels of caregiving demands for their child with intellectual disability also reported more personal growth and maturity." The Canadian scholar Dick Sobsey, himself the father of a disabled child, and his colleague Kate Scorgie write, "Parents of children with relatively mild disabilities may be more likely to adjust or accommodate by making minor or superficial changes. Conversely, parents of children with more severe disabilities may find it more difficult or impossible to go on with their lives as before and, as a result, may be more likely to undergo transformations." Positive transformations are achieved when initial disequilibrium, which is traumatic and brief, gives way to psychic reorganization, which is gradual and enduring. It would appear to be true that what doesn't kill you makes you stronger.

Those men and women who believe that parenting a disabled child has given them knowledge or hope they wouldn't otherwise have had find worth in their lives, and those parents who don't see such possibilities often can't. Those who believe their suffering has been valuable love more readily than those who see no meaning in their pain. Suffering does not necessarily imply love, but love implies suffering, and what changes with these children and their extraordinary situations is the shape of suffering—and in consequence, the shape of love, forced into a more difficult form. It doesn't really matter whether the meaning is there; it matters only whether it is perceived. Delusions of physical health may be delusions; someone who has congestive heart failure will probably die from it whether he believes that he has it or not. Delusions of mental health are more robust. If you believe that your experiences have vitalized you, then they have; vitality is an interior state, and experiencing it is its own truth. In one study, mothers who construed advantages from having premature babies experienced less psychological pain and were more responsive to their children's needs, while those who saw no advantages in the experience had children who were doing less well at age two. A study that looked at children with various complications at birth found, simply, "The children of mothers who had tried harder to find meaning had a better developmental outcome."

The world is made more interesting by having every sort of person in it. That is a social vision. We should alleviate the suffering of each individual to the outer limits of our abilities. That is a humanist vision with medical overtones. Some think that without suffering the world would be boring; some, that without their *own* suffering the world would be boring. Life is enriched by difficulty; love is made more acute when it requires exertion. I used to think that the nature of the challenge was extremely important. In my last book, I wrote about how at some level I loved my depression because it had tested my mettle and made me into who I am. I now think I could have had the same enrichment from having a child with Down syndrome, or having cancer. It is not suffering that is precious, but the concentric pearlescence with which we contain it. The raw grit of anguish will never be in short supply. There is enough of it in the happiest life to serve these instructive purposes and there always will be. We are more sympathetic to Holocaust survivors than to malcontent children of privilege, but we all have our darkness, and the trick is making something exalted of it.

We say that our struggles have ennobled us, but we don't know who we would have been without them. We might have been equally wonderful; our best qualities might be inherent rather than circumstantial. Nonetheless, most people look back even on unhappiness with nostalgia. I once accompanied a Russian artist to visit his elderly mother in Moscow. When we arrived at her apartment, we found her watching a Soviet propaganda movie from the 1940s on TV. I said to her, "Nadezhda Konstantinova, you were sent to the Gulag in that exact time, on the basis of that exact philosophy. And now you sit around watching that for entertainment?" She smiled and shrugged her shoulders. "But it was my youth," she said.

The question I was most frequently asked about this project was which of these conditions was the worst. From my own perspective, some conditions seem tolerable; some, desirable; others, terribly difficult. Bias varies, and other people revel in ways of being that I find frightening. I understand, therefore, why my own way of being frightens some people. Difference and disability seem to invite people to step back and judge. Parents judge what lives are worth living, and worth their living with; activists judge them for doing so; legal scholars judge who should make such judgments; doctors judge which lives to save; politicians judge how much accommodation people with special needs deserve; insurance companies judge how much lives are worth. Negative judgments are not confined to people who perceive themselves to be in the mainstream. Almost everyone I interviewed was to some degree put off by the chapters in this book other than his or her own. Deaf people didn't want to be compared to people with schizophrenia; some parents of schizophrenics were creeped out by dwarfs; criminals couldn't abide the idea that they had anything in common with transgender people. The prodigies and their families objected to being in a book with the severely disabled, and some children of rape felt that their emotional struggle was trivialized when they were compared to gay activists. People with autism often pointed out that Down syndrome entailed a categorically lower intelligence than theirs.

The compulsion to build such hierarchies persists even among these people, all of whom have been harmed by them. Halfway through my writing of this, a mother who had spoken to me freely about her transgender teenager's autism agreed that I could refer to him as male; she had originally asked me to avoid the issue of his gender because the prejudice against trans people and potential for hostile scrutiny terrified her. As I got to the end of the writing, a woman I'd known well as the mother of a transman admitted that her son was on the autism spectrum; she had not mentioned this previously because she thought the stigma was too significant. There is no consensus on what can be talked about and what needs to be hidden. Tobin Siebers makes a moving case for horizontal solidarity by pointing out that our disdain for people who cannot care for themselves is rooted in a false proposition. He argues that inclusion of disabled people "exposes the widespread dependence of people and nations on one another, dispelling the dangerous myth that individuals or nations exist naturally in a state of autonomy and that those individuals or nations that fall into dependence are somehow inferior to others."

The beautiful mosaic of multiculturalism was a needed antidote to the melting pot of assimilationism. Now it's time for the little principalities to find their collective strength. *Intersectionality* is the theory that various kinds of oppression feed one another—that you cannot, for example, eliminate sexism without addressing racism. Benjamin Jealous, president of the NAACP, the nation's oldest civil rights organization, told me how galling it was to him, growing up in a white town, when he and his adoptive brother were taunted for being black—and how much more distressing it was when some of the people who didn't patronize them for their race went after his brother for being gay. "If we tolerate prejudice toward any group, we tolerate it toward all groups," he said. "I couldn't have relationships that were conditional on excluding my brother—or anyone else. We are all in one fight, and our freedom is all the same freedom."

In 2011, gay marriage became legal in New York State after several Republicans in the state Senate agreed to support it. One of them, Roy J. McDonald, said that he had changed his stance on gay marriage because he had two autistic grandchildren, which had caused him "to rethink several issues." Jared Spurbeck, an autistic adult, thought his own quirks were "a sign of sinfulness" when he was growing up in the Mormon faith; when he started reading about gay Mormons, he found their experience much the same as his. "I couldn't ignore the parallels between autism and homosexuality. Once I'd accepted the one, I couldn't not accept the other."

I encountered activists of every stripe while I did this research and admired them even when I occasionally found their rhetoric expedient. The changes they sought seemed, individually, restricted to their particular province and experience, but as a group, they represent a rethinking of humanity. Most parents who become activists do so because they want to spur social change, but that impulse is never unalloyed. Some find it a relief because it gets them out of the house and away from their child without their having to feel guilty about it. Some use activism to distract themselves from grief; parents often laud what they rue most about their children to defend against despair. But just as belief can result in action, action can result in belief. You can gradually fall in love with your child, and by extension with that child's disabilities, and by further extension with all the world's brave disadvantages. Many of the activists I met were determined to help other people because they couldn't help themselves. Activism successfully displaced their pain. By teaching their learned optimism or strength to parents reeling from a recent diagnosis, they fortified it in their own families.

I understand this strategy firsthand, because writing this book addressed a sadness within me and—somewhat to my surprise—has largely cured it. The best way to get through these horizontalities is to find coherence, and in the wake of these stories, I recast my own narrative. I have a horizontal experience of being gay and a vertical one of the family that produced me, and the fact that they are not fully integrated no longer seems to undermine either. Some impulse toward anger at my parents evaporated, leaving only trace residue. In absorbing stories of strangers' clemency, I realized that I had demanded that my parents accept me but had resisted accepting them. Once I did, I was glad to have their ubiquitous company. The playwright Doug

Wright once said that family inflicts the deepest wounds, then salves them the most tenderly. When I realized there was no refuge from my parents' meddling, I learned to value it over loneliness and call it love. I started my research aggrieved; I ended it forbearing. I set off to understand myself and ended up understanding my parents. Unhappiness is a constant grudging, and in these pages, happiness served as a spur to amnesty. Their love always forgave me; mine came to forgive them, too.

I know that who I was appalled my mother and concerned my father, and I used to be furious at them for not embracing this horizontal part of me, for not embracing the early evidence of it. Writing has been a lesson in absolution, because I have seen the valiance love takes. Acceptance was always easier for my father than it was for my mother, but that was not particular to me; he accepts himself more readily than she did herself. In her own mind, she always fell short; in my father's own mind, he is victorious. The interior daring of becoming myself was my mother's gift to me, while the outer audacity to express that self came from my father.

I wish I'd been accepted sooner and better. When I was younger, not being accepted made me enraged, but now, I am not inclined to dismantle my history. If you banish the dragons, you banish the heroes—and we become attached to the heroic strain in our personal history. We choose our own lives. It is not simply that we decide on the behaviors that construct our experience; when given our druthers, we elect to be ourselves. Most of us would like to be more successful or more beautiful or wealthier, and most people endure episodes of low self-esteem or even self-hatred. We despair a hundred times a day. But we retain the startling evolutionary imperative of affection for the fact of ourselves, and with that splinter of grandiosity we redeem our flaws. These parents have, by and large, chosen to love their children, and many of them have chosen to value their own lives, even though they carry what much of the world considers an intolerable burden. Children with horizontal identities alter your self painfully; they also illuminate it. They are receptacles for rage and joy—even for salvation. When we love them, we achieve above all else the rapture of privileging what exists over what we have merely imagined.

A follower of the Dalai Lama who had been imprisoned by the Chinese for decades was asked if he had ever been afraid in jail, and he said his fear was that he would lose compassion for his captors. Parents often think that they've captured something small and vulnerable, but the parents I've profiled have been captured, locked up with their children's madness or genius or deformity, and the quest is never to lose

compassion. A Buddhist scholar once explained to me that most Westerners mistakenly think that nirvana is what you arrive at when your suffering is over and only an eternity of happiness stretches ahead. But such bliss would always be shadowed by the sorrow of the past and would therefore be imperfect. Nirvana occurs when you not only look forward to rapture, but also gaze back into the times of anguish and find in them the seeds of your joy. You may not have felt that happiness at the time, but in retrospect it is incontrovertible.

For some parents of children with horizontal identities, acceptance reaches its apogee when parents conclude that while they supposed that they were pinioned by a great and catastrophic loss of hope, they were in fact falling in love with someone they didn't yet know enough to want. As such parents look back, they see how every stage of loving their child has enriched them in ways they never would have conceived, ways that are incalculably precious. Rumi said that the light enters you at the bandaged place. This book's conundrum is that most of the families described here have ended up grateful for experiences they would have done anything to avoid.